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# Community-based organizations' perspective on health information outreach: a panel discussion\*

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**Objective:** A panel was convened to elicit guidance for librarians in initiating and implementing community-based health information outreach.

**Participants:** Participants included a panel of individuals from communities or community organizations who represented the types of groups with which librarians or information specialists need to interact and an audience who represented health sciences libraries, public libraries, academic institutions, government agencies, funding agencies, and community-based organizations and could contribute to a discussion on community-based health information outreach.

**Program:** The panel was presented with a hypothetical community setting and asked to respond to a series of questions: What do librarians need to learn about the community before they make their visits? What methods of outreach have been successful in your work? How would you implement and sustain a health information program in your community? How would health information interventions reduce racial and ethnic disparities in health?

**Main Results:** The panel helped to frame many of the issues that may confront librarians as they initiate information-related programs in communities.

**Conclusion:** There is clear consensus on the need for librarians to make the effort to reach out into the community, to make the contacts, to seek to understand the community, to talk with leaders, and to respect the community as they promote and teach the use of health information resources. It was confirmed that librarians and libraries have an important role in diminishing health disparities by improving access to health information.

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Traditionally, libraries have been perceived as places that people go to to find books or other materials; the librarians are there to answer questions and help the

users find what they need. More recently, the library has been seen not only as a place, a community space, but a concept. Librarians deliver information or present training to the people in their organizations but generally only to the people who ask for these services. Outreach requires us to remove ourselves from our traditional spaces and enter someone else's space—

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their community. In addition, community-based outreach is participatory, and, to develop appropriate relationships, librarians and other information providers must work with those who are going to use the information. Librarians may feel like "strangers in a strange land" when they leave their institutional setting and mix with community members on their own turf. Outreach is something we need to learn how to do well, so that we can be effective at meeting the information needs of those who need our services. Community-based outreach requires that we rely on partners from the local community to serve as our guides through the process of developing relationships, identifying needs, and becoming trusted associates.

### THE COMMUNITY-BASED OUTREACH PANEL

The panel included individuals from communities or community organizations that are representative of the types of groups with which we, as librarians or information specialists, need to interact. While no single individual can represent an entire community—geographically, ethnically, or any other way—collectively the panel helped frame many of the issues that may confront us when we attempt to initiate information-related outreach programs. The panel enabled us to hear the voices of some of our community partners, in their own words. The panel was presented with a hypothetical community setting and asked to respond to a series of questions designed to elicit some guidance to librarians in initiating and implementing information outreach in various types of communities.

The questions served to prompt discussion not only among the panel members, but also among other symposium participants, who represented a wide variety of community and library settings. Questions ranged from how librarians might approach a community, what they need to learn and how to learn it, and very importantly, to whom they should talk. The panel and the audience then discussed methods that they could use to implement outreach programs. Although the panel did not have an opportunity to discuss evaluation of outreach programs, later presenters at the symposium did, and their presentations appear elsewhere in this supplement.

#### Panel moderators and members

The panel session was moderated by Roy Sahali, outreach coordinator, Pacific Northwest Regional Medical Library, University of Washington, and Karyn Pomerantz, research scientist, School of Public Health and Health Services, George Washington University. Members of the panel were:

- Byllye Avery, founder, Black Women's Health Imperative and the Avery Institute for Social Change, New York, New York
- Rogene Gee Calvert, president-elect, Friends of Houston Academy of Medicine-Texas Medical Center Library, and board member, Asian American Health Coalition

- Eduardo Crespi, director, Centro Latino de Salud Educación y Cultura, Columbia, Missouri
- Judith S. Mikami, director of development, Na Pu'uwai Native Hawaiian Health Care System, Molo-kai, Hawai'i
- Buford Rolin, vice-chair, Poarch Band of the Creek Indians; member, National Indian Health Board; and chair, National Congress of American Indians President's Task Force on Health Information and Technology

#### The scenario

Once upon a time, there was a community where people worked very hard but had a difficult time supporting themselves. Few people found attractive and affordable housing, and many worked in jobs that provided essential services to their community but barely covered their essentials. Money was unavailable to improve the schools, which were terribly run down and depressing. Many children graduated without basic reading skills. The people's health reflected the stress and lack of economic opportunities. People self-medicated the best they could. Diabetes and hypertension rates soared, and HIV and AIDS rates grew among the young people. In spite of all these problems, neighborhood organizations flourished with tons of opportunities for people to interact in local politics, social events, churches, and clubs. People got involved in many activities: seniors gathered every day to play cards and practice tai chi, children attended choir rehearsals, teens congregated at the recreation centers, and the community library welcomed everyone to use its resources. Several health centers opened their doors to treat primary care problems and HIV infections and AIDS and sponsored health fairs and talks.

The town council discovered that there were many different rates of diabetes, HIV, and other conditions among different groups in their neighborhoods. They published reports about disparities in health and health care and problems with health literacy. Money flowed into universities to study these problems and to help out. Money also flowed into some of the neighborhood organizations so they could plan their own programs. People wrote grant proposals like crazy, trying to forge alliances among different groups of people and institutions to provide communities with skills to access health information. Several local librarians got together and decided to help their community access and use good health information at local sites. They knew a great deal about health disparity reports and statistics but needed to learn more about the practical aspects of working outside their walls. They were thrilled to leave the reference desk to go out and meet all the people who never entered their stacks. After doing preliminary research, they made appointments with the directors of several organizations to discuss ways they could help increase people's understanding of health issues and create healthier conditions in their town.

## THE PANEL DISCUSSION

Panelists and audience members responded to key questions about outreach in community settings. The purpose of the session was to discuss different approaches that libraries and community-based organizations can take to implement health information programs. In addition to developing relationships and partnerships around health information access, important issues included sustainability of projects.

### What do our librarians need to learn about the community before they make their visits?

*The panel members emphasized the importance of learning about the community before visiting and particularly before trying to start any projects or programs in the community. The clear consensus of the panel was that while it was absolutely essential to learn about the community through research, such as reviewing local newspapers and Websites before coming in, it was most essential to visit the community in person. Further, the librarian or other outsider must approach the right community leaders.*

**Rolin.** The first step is to come into our community and see our tribal leaders. They will make an introduction to the community and involve the community in the process and will decide how we can assist in the process.

**Mikami.** For Molokai, it is similar to Buford's recommendation. About 65% of the population is native Hawaiian. Before coming with a specific agenda, I would say contact the leaders of the community, but we call them kupuna. They are the revered elders of the island. The person that comes in would have to learn about the community, what makes up the local culture, what the local culture is, and what the accepted protocol is—for us, we call it “talk story.” You can read and have telephone conferences, but you don't get the flavor—I think everybody needs to have a face-to-face. Even videoconferencing does not really help.

**Crespi.** In any population you need to build trust and establish a rapport, especially when it has to do with public health issues that are sensitive, like family planning and HIV. To do that you have to visit with people. In our Latino population, a large percentage are not properly documented. They don't feel comfortable with government agencies. That is why we have to customize the services of the government agencies for our Latino families to be comfortable. Human contact is definitely the best.

**Gee Calvert.** I echo what everyone said. It is very challenging when you go into a community like this [Houston's Asian population] where it is not obvious who the leadership is and there is no one leader. My advice is before there's a motive, before there is an agenda, participate in their traditional activities—somehow partner with them on other things. If you wait until there's a reason, an agenda, a grant, it is a

little too late. Build the relationship of trust first. There are over twenty-five different ethnic groups among Asian Americans. The languages are different, different religions, different practices, so a little homework would not hurt either—just book studying about the history and political processes of some of the cultures. You can walk into things that you're not aware of, such as political mistrust between groups.

**Avery.** I think people have to first get themselves prepared before entering the community. Know in the first place that you do not know. Know that the community has the answers. They are the experts. Also know that when you come to a community you are coming to learn. The second point is you need to find out what research has been done in the past. What have been the outcomes of those relationships? The communities of color, African American communities in particular, have been studied to death.

**Rolin.** In our Indian communities, that is very important because we know what our needs are. A lot of people are of the perception that the Bureau of Indian Affairs and the Indian Health Service control all activity on the Indian reservations. In some sense, they do. But for other situations that happen in my community, I can tell you right now, if someone came to the city of Atmore, Alabama, looking for the Poarch Creek Indians, they will send them out to the tribal leadership. It is very important that we know who is coming into the community and what is going on, we being the leadership of the tribe. We give our tribal members the comfort of knowing that we are not going to work with anyone who will pull anything fast on them.

**Avery.** Entering a community is very important. It is important to make sure that the organization that you are entering with is well respected in the community. The population most of us are addressing are people who have been pushed around by society. They have had negative experiences in school, they're disenfranchised in a lot of ways, and it is very expensive, time-consuming work because you're not starting off with people who are at zero, you're starting off with people who are at negative ten. There is nothing like cosponsoring events, showing up, asking “What can we do? How can we be helpful to you? This is what we have, and can you use it?” before you ask for anything in return.

*Although the focus of this question was the work it was necessary to do before starting a project, one suggestion from the audience was that funders factor time into grants to enable the development of relationships. Another audience member spoke up for small “mom and pop” organizations that operate at a very grassroots level. They are the ones who know exactly what is happening in their community, rather than the larger national or academic organizations or institutions.*

### What methods of doing outreach have been successful in your work?

*The panel members and the audience described many creative and innovative methods of doing outreach, with a great deal of emphasis on pairing information outreach with other activities and involving the prospective audience for the outreach. Because children and education are highly valued by many of the communities, a number of the described methods related to children, education, or educational institutions.*

**Avery.** A lot of communities have health fairs, and there's nothing more powerful than having a computer there when someone finds out their cholesterol is up too high or their blood pressure is up and with your computer you can print them out information.

**Crespi.** What we did to start communicating with our population was to contact the Department of Education and the local school district. In that way we were able to send information to the parents, and, in 3 days, we covered 23 schools, 268 Latino children, and approximately 150 families. In the following week we had approximately 70 phone calls from parents interested in coming to the center to learn English.

In terms of public health, we partnered with the local health department and we established a local women, infants, and children (WIC) program in our center once a month, so they didn't have to desperately look for interpreters when a Latino woman went to the health department. It has been successful for the last five years. That was another strategy, partnering with the agencies in order to reach the population. Also, we help our Latino population save energy by recommending that they not go to agencies where they are denied service. For instance, if a family does not have proper documentation, we tell them, "Do not go to the [Department of Health and Human Services] (DHHS), because it is a waste of energy. Don't try to get a driver's license—it is a waste of energy." I think one of the best strategies is the truth.

**Gee Calvert.** I would like to capitalize on that, the win-win strategy where everybody gets something that they want or need. In Houston, we had the ingredients for success because we had a funding body, the Friends of the Texas Medical Library, to raise money. They were enlightened. We had our library that had the expertise and was enlightened enough to know they had to reach out to the different cultural groups. And the group I represented, the Asian American Health Coalition, was a community-based group that could get into the community. We partnered and came up with what we called CHIA, Consumer Health Information for Asians.

We started by putting eight paper kiosks in different parts of the community, four in the Chinese and four in the Vietnamese community, since those were the two largest groups at the time. Since that time we have moved into electronic kiosks and have added Korean as well as Chinese, Vietnamese, and Spanish pamphlets. The material is in their native language and it

is simple. We spent a lot of money translating and validating the information to make sure it was comprehensible and appropriate.

*The audience described several strategies:*

- Give the same program at different times during the day for different audiences—middle school students, teachers, and parents. The parents were urged to attend by their children, who were there earlier. This strategy takes advantage of the fact that in most communities parents will do quite a bit more for their children than they might otherwise.

- Make the information professional part of the health care team and identify others, both individuals and organizations, that the community goes to for information.

- Identify who does basic adult education, how and where it is done—in classes or individual tutoring—and try to collaborate with the teachers or developers of these programs. Health literacy is an important part of general adult literacy, and health programs can be part of general literacy education. However, if this is done, the materials presented, whether in a classroom setting, in a field trip to the library, or at a health fair, should be at a level comfortable for those classes.

- To meet potential partners and collaborators, first become known and build up credibility in the community or with a set of community leaders or members. For example, if a librarian regularly participates in a meeting or conference in the state or region, eventually he or she will become known and the participants will see the information resources and understand the potential. The opportunities for collaboration will be recognized. An audience member used this strategy successfully with her state's rural health association.

- Attend health fairs, conferences, or community events. A librarian or information specialist may not be able to attend every one, but community members can take the information from the librarians and spread it further.

- Identify the learning styles and individual information needs of your audience and find simple, yet memorable, ways to meet those needs. For example, go into individual homes with a laptop and projector to show families how to access good health information.

- Collaborate with other organizations to reach more people.

- Work with local politicians. A group successfully lobbied county commissioners to build libraries and health centers in each district. Libraries and health centers are located near each other and interact, thus, increasing use of the public libraries.

- Use health agencies in the community as coalition builders for the community. Potential partners include health education programs at universities and the health educators' professional organization, the Society for Public Health Educators. Health educators are the people who work at health fairs. Nursing programs and programs in policy areas are also likely partners for health information outreach.

- Partner with a public health department. The Denver public health department's Healthy People 2010 program was an invaluable partner in the success of the Denver Public Libraries outreach project. The health department provided the public health expertise and recommended the health educator who was already known and trusted by the community.
- Mobilize special interest lobbying across ethnic lines to influence legislation. For example, other ethnic groups would support the passage of the Indian Health Care Improvement Act.
- Reach children and their families by educating staff of Head Start centers, day care centers, preschools, and licensing agencies for day care and preschools and doing the same with the school boards, principals, school media center librarians, and curriculum directors. Each has a national association that could be part of the strategy to reach these professionals.
- Take advantage of two National Center for Minority Health and Health Disparities programs: EXPORT, a centers of excellence project, doing research and training on health disparities in communities, and a scholarship for doctoral graduates to do research projects on health disparities. Both programs offer potential resources for health information outreach.

*Donald A. B. Lindberg, director of the National Library of Medicine, asked whether approaching health information literacy through the educational process would be reasonable, because several speakers indicated that education of the young appears to be important to all communities.*

**Gee Calvert.** I think it is not a simple answer. People may be worrying about their next meal or other things in their family. So we as community service providers have to identify assets in the community where, as someone said, we can work collaboratively to assist the children in the community. It may be very indirectly related to the reason we are here today, improving the knowledge of health and improving health in general, but we cannot get there until you have dealt with the basics.

**Crespi.** Of course, Latinos have some problems that other people do not, their immigration status. That is a big obstacle preventing our Latino children from continuing their education. Often I have kids finishing high school and coming to the Centro Latino with their parents asking me if I know of any institution where the kids can go and continue their education. Again, I have to tell them the truth, and the truth is no. What I'm looking at is our future generations. The kids being born here, they are US citizens. We are implementing a program right now that is called "Each One Teach One." There is nothing better than young people helping each other, role models. We have university students being tutors for the high school kids for our teen tutoring program, and then our teens, the ones that excel in our tutoring program, help our little ones.

In order for us to be able to implement MedlinePlus

statewide, we need to talk directly with the Department of Elementary and Secondary Education and have them include MedlinePlus as a research tool for our high school students. We will affect thousands of young people who will use MedlinePlus and will be interested in a future in health careers.

**Mikami.** I echo what Eduardo said and Rogene. If you are worrying about your next meal, you're not going to go and want to get health information until there is a crisis. I can see, as the day has gone on, that to educate our young because we want to influence them, makes working with our community colleges, working with the organizations that have access to health information resources, important. However, not only do the resources have to be culturally appropriate, but training must be made available to the people living there. They are the ones who are going to work with the kids, work with the schools. We need those role models to show us and the students that there are many possibilities out there.

This is a little bit off of the subject, but we can demonstrate the need for grants. We have a disparate population; our health statistics are bad. We can get the grants but we don't have the people to run the grants because we don't have the expertise there [on Molokai]. One of our challenges is to train our people or for our students to go out and get educated but to come back and work in the communities. A lot of students have the desire to go out, but they're so unexposed that they can't adapt to life in Honolulu, in an urban environment, in a city.

**Rolin.** I tell you when we look at what is happening in our tribal community, education has made a difference. It is so wonderful to be able to have on our reservations our own physicians who have been able to access resources through either public service or through the tribe to go and get a formal education and come back and be involved. It is wonderful to see in the levels of bureaucracy, whether it be the Bureau of Indian Affairs or the Indian Health Service, to see those professionals are now working with the Indian programs. But the key is that we have to educate our own. In my tribe alone, it is wonderful—out of 2,300 people, we now have 15 attorneys. We're going to soon have 2 doctors. That is fantastic for us, a small tribe. We know that for things to improve we have to be a part of it. We certainly encourage that through all of our organizations.

**Avery.** In addition to educating the school boards, it is important to educate the teachers, because a lot of the children have a lot of diseases that they need to be learning about. Do not make an assumption that the teachers know how to teach the children about diabetes, because they do not. I like the strategy of talking to the school board and educating the teachers and then educating the children.

**Lindberg.** Someone was saying you need models and examples, and I think that is exactly right. Think about Profiles in Science, which is online and made available by [the National Library of Medicine] (NLM). It starts out with Nobel Prize winners and a description of how the discoveries were made. But I have to tell you that half of those Nobel Prize winners are the sons and daughters of immigrants. They are people who did not have two dimes to rub together when they tried to get themselves into a college. Another model is "Changing the Face of Medicine," an exhibit in the NLM building that describes the achievements of women in medicine. You will find many minorities there as well.

### How would you implement and sustain a health information program in your community?

*Panelists proposed integrating a health information component into existing efforts and described programs in their own communities that would be enhanced by adding health information. Teaching children was also seen as a way to introduce health information to the community. Gee Calvert and Crespi talked about coalition building to implement a project.*

**Mikami.** Our [Area Health Education Center] (AHEC) received a grant that helps students come every summer to Molokai. They come to a rural area as part of an interdisciplinary team to work among the people. When you think of the health care team you have nurses, doctors, pharmacists, dieticians, and so on, but I see a real viable link with librarians, because team members are always looking for health information. Librarians can inform them on the best way to tap into that.

**Avery.** We have a pilot program in four United Methodist churches in Harlem. Our goal is to strengthen the health committees that already exist in the churches. During Lent, they will talk about 40 things that people can do during the 40 days of Lent to better their health habits: walk 10,000 steps a day, stop using salt, don't eat white food, no sugar. They will have a daylong workshop session at the church, where they will have 6 or 7 stations and 1 will be around health literacy. I have been sitting here circling the names of all the people in New York City—I will be calling you. We want that MedlinePlus exhibit set up!

**Rolin.** I think it [health information] is important. A Website, so our young people could access it for doing their research papers, would definitely enhance what we have now in the way of information technology and computer systems.

**Mikami.** I think a link would be the children. Many of our families are multigenerational, so I can see that the children could be the carriers of information in the home.

**Gee Calvert.** We have so many different groups that speak different languages, and we would work with

all the different ones to launch something like that [health information program]. But you have to have trust, because it is easy for something to go wrong. If something does come up, with trust you can feel comfortable discussing it and hopefully resolving it. You do not need to build another organization. I encourage people to partner with larger groups, institutions, universities, hospitals, libraries. I think that is a great way to go. That is a good way for small groups to get started.

**Crespi.** For my community, I would do research on the people who are interested in working with NLM and working with MedlinePlus. After I have that, I would ask the interested parties to come up with their own budget. Then we would have a realistic picture of how much it would cost to implement the program. Once we have that, we can think about how we're going to sustain the program.

*Panelists agreed that funding is necessary for sustainability, but working with those who have a common vision and who value the project was seen as more important and a way to get sustainable funding. Having expertise reside in the community was seen as a factor in sustainability.*

**Gee Calvert.** Money is important, and we would have to look for the funding, but again coalition building and the coalition approach is very fundable. I caution everyone not to build a coalition around funding. That is not a stable way of keeping it going. You have to have the common vision and the common mission. You have to be fair with each other. In the coalition I worked with, it was important that all the different groups were represented and that the leadership rotated. It was not just held by one group. They [coalition members] cannot be a silent partner in a coalition either. You have to pay attention to all of those things to make your coalition work well.

**Crespi.** I believe it is more important to sell the idea first, convincing people that the project is very important for the whole community. I am talking about doing it in such a way that, for instance, the Office of Minority Health will get involved, that the Department of Education will get involved, that even the governor will personally get involved in the program. Once they understand that it is important and it is politically correct to help, then I think you'll find sustainability. But—also I need two or three grant writers who are going to write the grants, the proposals. I am good at communicating with people and doing public relations, but I am not a great writer.

**Rolin.** My tribe has gaming, and we've set up discretionary funds. We could sustain it [health information access] with the discretionary funds.

**Mikami.** We need the resources and a trainer, because people are not necessarily computer savvy, and the economy is poor so people don't really own comput-

ers. We need training because we want it to be sustained on Molokai, and you cannot live on grants forever.

**Rolin.** There is a need for us, too, for the various departments to find and bring back training and information and share it with the community so that it could be sustained in the community.

**Noting that health information does not substitute for health services and healthy conditions, how would health information interventions and outreach reduce racial and ethnic disparities in health? How can librarians become more involved in this effort to reduce racism and to advocate health for all?**

*The audience reaffirmed the importance of health information in reducing health disparities and suggested assistance that librarians, both health sciences and public librarians, could provide.*

- Librarians “hold the key” to accessing health information and knowledge. With access to information, people are empowered to take control of their health. To do this, librarians need to go out, meet people where they are, and help them find the health information they need. Health disparities can be significantly reduced when people have credible information.
- Health literacy builds self-worth and enables patients to ask questions of their health care providers to better understand their condition and the care they are receiving.
- Librarians can support the cultural competency training at health sciences schools by providing resources for curriculum chairs and deans.
- Librarians can provide resources for health professionals who are doing health care outreach to the community.
- Librarians can help people access affordable and culturally sensitive health care as well as health information. This service is especially valuable for refugee and immigrant communities, who may not know that they are entitled to health services.

*Avery responded a question from the audience on racism that institutional racism increases health disparities. She ended the session by charging those who work in community-based health information outreach to be advocates for their communities in their own institutions, thereby reducing health disparity and racism.*

**Avery.** As you do your work in communities of color, what we need is for you to become allies on our behalf, which is also on your behalf. Librarians need to be able to articulate the critical health issues for every single one of us. We don't have to be at the table to know that what concerns black women is on the table. Because you are there. Because you know it. You have had your feet under the table. You have been in the circle. All of our work contains an element of social

justice. I don't care what it is you do, social justice is a part of it.

## CONCLUSION

The community-based organizations represented on the panel and in the audience would definitely welcome health information outreach in their communities and with their organizations. Librarians need to make the effort to conduct community outreach. The panel invited them to go out into the community, to make the contacts, to seek to understand the community, to talk with leaders, and to respect the community as they carry out their outreach efforts.

The rapport needed for this type of outreach requires time. It is even better if librarians can walk the neighborhood, participate in activities, and become trusted in the community before an outreach project is started. The panelists described efforts already under way that would be enhanced by a health information component and that a librarian could provide assistance to now. The ease with which the panelists suggested projects where health information would fit also confirms another recommendation. If the librarian is willing to listen, the community will take the leadership role in determining how best to improve access to health information in the community. Community organizations are ready to combine in equal partnership their knowledge of the community and their established relationship with the community with the librarian's health informatics knowledge and experience.

If the libraries' and the partnering organizations' goals are the same, panelists and audience members agreed that any organization with an established presence in the community would make a good partner. Suggestions on whom to collaborate with included government agencies, health agencies, support groups, professional organizations, education agencies—from preschools to universities to adult education. There are so many possibilities that a community assessment is a recommended first step.

Ten years ago, access to health information would have generated comments about availability of computers and connections to the Internet in the community, but only one panelist mentioned that this was an important issue. For those who lack connectivity at home, public libraries, schools, and community and technology centers now provide access to computer resources. Only one panelist mentioned needing assistance with grant writing, although all panelists were from organizations with experience in obtaining government and foundation funding. Participants acknowledged the importance of funding but pointed out that human and knowledge resources were even more important in sustaining health information access in communities. Training those who reside in the community, so the expertise is local, was mentioned more than once.

Representatives from community-based organizations voiced the opinion that increased access to health

information by minority and underserved populations would translate into improved health decisions and behaviors that ultimately would result in reducing health disparities. They clearly confirmed that librarians and libraries intending to diminish health disparities by improving access to health information would do well to establish partners with community-based organizations. It is also heartening to note that community groups readily endorse the role of librarians and libraries in reducing health disparities and see

this outreach as compatible with and complementary to their own efforts.

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